Facing the challenge of rheumatoid arthritis

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The differential effects of rheumatoid arthritis on distress of patient and partner.

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Abstract

This cross-sectional study investigates primary and secondary stressors of distress in rheumatoid arthritis patients and partners, analyzing data of 61 couples. Patient's disability was found to be a primary stressor of her/his own distress. It has an indirect effect on partner's distress through partner's primary stressor, perceived burden. Marital quality and negative transactions can be considered joint secondary stressors for partners, not for patients. An indication of an indirect effect of marital quality on patient's distress was found, through partner's burden. Using a multilevel model, which takes into account the dependence between patient's and partner's distress, 36% of the variance in patients' distress could be explained, whereas 68% of partners' distress variance was explained. More knowledge on how patient and partner influence each other's distress is needed to develop psychosocial interventions that will help patient and partner minimize their psychological distress and prevent deterioration of their marital quality.

Introduction

Rheumatoid Arthritis (RA) is a chronic progressive disease of the auto-immune system with unknown etiology (1) and occurs two to four times more in women than in men (2). The disease is characterized by chronic inflammation of the joints, which results in most cases in damage and destruction of the joints. RA has an unpredictable course: patients experience times of 'flare-ups' during which they suffer, alternated with times of remissions during which they seem to recover (3). RA patients suffer from joint pain, stiffness and lack of energy and are therefore limited in their physical activities. They may lose the ability to adequately perform the tasks and roles they used to perform, such as household activities, occupational tasks (4), or leisure activities (5;6). Due to the unpredictable course of RA and the resulting restrictions in physical and social functioning, patients are confronted with uncertainty, threat and ambiguity (7), and decreased psychological functioning (8;9).

The diagnosis of RA is not an event that only occurs to the patient, but is a stressor that affects all his or her family members. It is unlikely that other family members ─ notably partners ─ remain untouched, since RA appears to affect all aspects of a patient's life, including functioning in the family. The partner, whose relationship with the patient is characterized by intimacy, interdependence and close proximity, may in particular experience more distress (10;11) and be burdened by the care to be provided to the sick partner (12;13). To stand by and observe their loved one struggle while being unable to alter the situation may cause feelings of helplessness (14). Especially if the patient's disability increases, partners may be confronted with new demands, i.e. new roles, new responsibilities, and caregiving tasks and reduction or loss of social and leisure activities (15). Each of the stressors mentioned above places the partner at risk for psychological distress.

To capture the mechanisms through which a certain stressor affects an individual, Pearlin and coworkers (16;17) introduced the concept of 'stress proliferation'. In general, stress proliferation refers to a process in which initial (primary) stressors generate other (secondary) stressors that are quite different from those faced earlier. People who are initially exposed to only one stressor or set of stressors eventually become entangled in multiple stressors. Primary stressors are hardships rooted in the situation whose effects are under study and secondary stressors are surfacing in the social, leisure and occupation realm. The variation in well-being frequently observed in people may be explained not only by a variability in primary stressors but also by a set of secondary stressors. The outcomes of this stress proliferation process may be

manifested in psychological distress. Sociodemographic characteristics are expected to influence each of these components of the stress proliferation process.

Applying the stress proliferation model to RA couples (i.e. couples in which one partner has RA), we expect that stress proliferation is an ongoing process since RA is a chronic disease and chronic strains either surface repeatedly or maintain their presence over a considerable period of time. Moreover, distress in one partner will affect the level of distress in the other partner because partners are assumed to have concerns about each other (18;19), although this mechanism was not confirmed in studies on depression in RA patients and their partners (10;20). Therefore, the stress proliferation model cannot be studied independently for patients and their partners, as primary and secondary stressors will affect both partners, in possibly different ways.

For RA patients, hardships and problems embedded in the illness and its development are considered *primary* stressors. Disability is often found to determine distress in patients (8;21;22). A *primary* stressor for partners of RA patients is the burden they experience. In the study by Walsh et al. (11), for example, the amount of burden experienced by the partner contributed to the partners' level of depression.

Secondary stressors for RA couples are particularly found in their interactions with each other, which may not always be experienced as supportive. When a patient is provided with more supportive transactions than (s)he actually needs and/or wants this may lead to a feeling of 'overprotection' or 'preferential treatment' (23) and more distress (24;25). Despite the partner's best intentions and possibly due to a lack of sensitivity on the part of the partner to the specific needs of the patients (26), social support is then perceived as unhelpful and problematic by the patient (27).

In this study we focus on the so-called *un*supportive transactions. In contrast with supportive transactions that are well-meant, unsupportive transactions entail negative social support such as negative responses and criticism. Critical remarks of one partner may be related to poorer mental health of the other partner (28). Since marital quality was found to be an important correlate of both patients' and partners' mental health (20;29), marital quality should also be considered as a secondary stressor affecting well-being.

Summarizing, the literature on distress of RA couples is small and not always consistent, which may be explained by the variability in the sets of primary and secondary stressors and by limitations of the study design and data analysis. The aim of this cross-sectional study is to gain a

better understanding of the mechanisms through which RA affects patients and their partners, in particular to investigate which primary and secondary stressors determine the patient's distress and which the partner's distress. Previous findings, mentioned earlier, showed that some stressors are important in explaining distress of the patient but not distress of the partner, whereas other stressors are more important in explaining distress of the partner. In line with previous findings, we hypothesize that disability is a *primary* stressor for patients but not for partners and that burden is a *primary* stressor for partners but not for patients. Furthermore, we hypothesize that negative transactions and poor marital quality are *secondary* stressors for both patient and partner. Because primary and secondary stressors may very well be interrelated, – for instance, in a bad marriage the burden experienced by the partner may be higher than in a good marriage – we also examine possible interaction effects of primary stressors, secondary stressors and between primary and secondary stressors.

Methods

Subjects

The present study is rooted in the framework of the 'European Research on Incapacitating Diseases and Social Support' (30). Four waves of data collection were carried out between 1990 en 1995 among RA patients recruited from 5 hospitals in the Netherlands. The present study is an extension of the EURIDISS project in the Netherlands and reports on the fifth wave of data collection among the remaining *same* patients, which was carried out in the summer and autumn of 2003.

According to the inclusion and exclusion criteria formulated at the start of the study (30;31) the first wave of data collection (T1) started with 292 respondents. Eight years after the fourth wave (T4), the remaining 268 patients were sent a self-report questionnaire. Of these patients 50 had died, and 16 had moved away, whereas 73 patients refused to participate. Consequently, 129 patients participated in the fifth wave (T5). Adjusting for the 66 patients who died or moved away, the response rate is 64% of the T4 participants.

At T5 it was the first time in this longitudinal study that the partners were asked to participate. They were sent a self-report questionnaire, if patients reported at T5 that they were married (n=93) or living together with a partner (n=3), except for two partners living in an elderly home. Twenty-two partners were not willing to participate. Therefore, of the 94 questionnaires sent to partners, 72 were returned, which gives a response rate of 77%. Due to

missing values on one or more study variables a sub-sample of 61 couples were used for the cross-sectional (T5) analyses. The sub-sample consisted of 20 (33%) male patients and 41 (67%) female patients and 41 (67%) male partners and 20 (33%) female partners. These couples were married for on average 34 years (sd=13.1).

Analysis of the non-response of the partners showed that the patients whose partners did not participate reported poorer marital quality (at T5) than patients whose partners participated ($t(88) = 1.9$, $p = .03$). Although perceived marital quality of the non-participating partners was not available, it is likely that, if the patient reported poor marital quality, the partner will also perceive their marital quality as poor, given the moderate correlation ($r = .45$ and $p < .05$) among the 61 participating couples. As a result, this latter group of marriages with poor marital quality may be underrepresented in our sample.

Measures

Distress. As indicators of distress the depression and anxiety/insomnia subscales of the General Health Questionnaire (GHQ-28) (32-35) were used and combined to one measure. Each subscale contains 7 items and the answer categories run from (1) not at all; (2) no more than usual; (3) rather more than usual to (4) much more than usual. Both subscales were presented to both patient and partner. Scores run from 14 to 56 and reliability (Cronbach's alpha) of the combined scale was .87 for the patients and .88 for the partners.

Functional disability (primary stressor). Functional disability of the patient was measured with the Groningen Activity Restriction Scale (GARS) (36;37). The GARS has 18 items divided across two subscales: an Activities of Daily Living scale (dressing, washing oneself, etc.) and an Instrumental Activities of Daily Living scale (household activities). The response categories run from: (1) fully independently without any difficulty; (2) fully independently but with some difficulty; (3) fully independently but with great difficulty; (4) cannot do it fully independently, only with someone's help; (5) cannot do it at all, need complete help. The categories 4 and 5 were merged into one, partly because category 5 was chosen by only a few patients. The scale runs from 18 to 72 and had a reliability of .95.

Partner Burden (primary stressor). The Caregiver Strain Index (38) refers to the intensity of the burden that a caregiver, – in our study the patient's partner, – experiences. Partners were asked to answer yes or no to 13 items concerning care, time and stress issues. The scale runs

from 0 to 13 and the reliability of the scale was .72. The higher the index score, the higher the perceived burden.

Negative Transactions (secondary stressor). To assess the perceived negative transactions we used the negative transaction items of the Social Support List of Van Sonderen (39), consisting of 7 items. The patients were asked about the negative transactions with their partner. The same instrument was used to assess the negative transactions of the partner with the patient, as perceived by the partner. Negative transactions were rated on a 4-point scale. The scale runs from 7 to 28 and reliability of the scale was .68 for patients and .74 for partners. A higher score refers to more negative transactions.

Perceived Marital Quality (secondary stressor). Marital quality was measured with the Maudsley Marital Questionnaire (MMQ) (40). This 10-item scale focuses on the communication with the partner, feelings of warmth and understanding, and satisfaction with the time spent together. Answer categories run from 0 to 8. Since the MMQ does not ask respondents about their satisfaction with their intimate and sexual relationship with their partner, we added two items to this scale. These two items were 'How satisfied are you with the intimacy with your partner?' and 'How satisfied are you with the sexual relationship with your partner?'. The scale therefore runs from 0 to 96. Both patient and partner filled in this questionnaire. Reliability of the adjusted scale was .92 and .93 for patients and partners respectively. A higher score refers to higher marital quality.

Demographics. The questionnaire asked patients and partners about their gender, age, education and marital status. In addition, patients were asked about the duration of their disease. Formal education was coded according to the ISCED (41) and recoded on a 6-point scale ranging from 1 (primary education) to 6 (university degree). Disease duration was measured at T1 as the number of years since the patient was diagnosed with RA, fulfilling at least four of the revised criteria of the American College of Rheumatology (42).

Analysis

Means and standard deviations of all study variables were calculated for patients and partners, and for men and women, separately. Differences between patients' and partners' distress scores and the norm score for the general population in the Netherlands[1] (43) were tested with t-tests.

[1] mean anxiety/insomnia is 5.8 and mean depression is 1.6 in a normal population (5.8 + 1.6 = 7.4 mean distress, adjusted for 1-4 coding: 7.4 + 14 points = 21.4) (43)

Because the norm scores were based on the 0-3 coding of the GHQ, its value of 7.4 was increased with 14 points to adjust for the 1-4 coding we used. Differences between patients and partners were tested with paired t-tests; gender differences in patients and partners were tested with t-tests. Correlations were computed for all variables, separately for patients and partners, and between patient and partner variables (within couple).

To provide a graphical representation of the data a method proposed by Bland and Altman (44) was applied to compare distress scores of patients and partners. Their method consists of a way of displaying the data in a plot in which the difference between two measurements is set out against the average of the two measurements. If the differences are normally distributed, 95% of the observations are expected to lie between the mean difference -1.96sd and +1.96sd, also called the 95% limits of agreement. The plot of difference against mean allows investigation of any possible relationship between the differences and the mean (e.g., heteroscedasticity) and shows any extreme and outlying observations. Following the Bland-Altman method we plotted the difference between patients' and partners' scores (distress patient – distress partner) against the average of the patient and partner scores ((distress patient + distress partner) /2).

Multilevel modeling was used to test our hypotheses. A two-level hierarchical linear model was constructed, where the dependence between patient and partner (level 1) distress scores is modeled through couple (level 2) membership. In the model, differential effects and variances are included for patients and partners, by using dummy variables, to acknowledge the different roles within the couple. Thus, the effect of primary and secondary stressors can be investigated separately for patients and partners, explicitly taking into account their mutual dependence. This model is also known as the APIM (Actor-Partner Interdependence Model) (45;46) and can be viewed as the simplest form of the social relations model (47). The analysis was carried out in MLwiN 2.0 (IGLS estimation). All independent variables were standardized, for patients and partners separately, which enables comparison of the effects among and between them. Deviance tests or likelihood ratio tests were used to compare the relative fit of the different models. The difference in deviance of two nested models has a χ^2 distribution with degrees of freedom equal to the number of extra parameters in the larger model. Results are considered statistically significant when two-sided p values are $\leq .05$. For patients and partners the percentage of explained variance can be computed. The percentage explained patient variance is the relative change in the total patient variance, which is computed by summing the

individual patient variance and the couple variance. It should be noted that these measures are not independent, because the couple – or common - variance is part of both patients and partners variance.

Results

Table 1 shows means and standard deviations of the measures for patients and partners and for females and males separately.

Table 1. Means and standard deviations for the total group and for females and males.

	Total group		Females		Males	
	mean	sd	mean	sd	mean	sd
Patient						
1. age	60.1	11.5	58.4	12.0	63.5	10.0
2. education	3.3	1.0	3.2	1.0	3.6	1.0
3. disease duration	14	1.4	14.0	1.3	13.9	1.6
4. disability	33.2	12.0	35.3	12.3	28.9	10.6
5. distress	19.6	5.2	20.5	5.4	17.9	4.2
6. negative transactions	8.9	1.9	8.8	1.9	9.3	1.9
7. marital quality	85.4	11.2	84.6	12.5	86.9	7.9
Partner						
8. age	59.8	13.8	60.5	10.2	59.4	15.4
9. education	3.2	1.0	3.0	.9	3.3	1.0
11. burden	3.1	2.4	3.0	2.8	3.2	2.2
12. distress	18.0	4.7	19.2	5.0	17.4	4.5
13. negative transactions	9.7	2.1	10.7	2.1	9.2	1.9
14. marital quality	81.3	14.2	80.7	12.9	81.7	14.9

Both patients and partners were on average 60 years at T5. The mean educational level was 3.3 and 3.2 for patient and partners respectively, indicating 9 to 10 years of formal education. Patients had had RA for 14 years on average. Patients' adjusted mean distress score (19.6) was significantly lower than the mean found in the general Dutch population ($t(60) = 2.7$, $p \leq .01$). Partners' mean distress score (18.0) was also significantly lower than the mean found in the general population ($t(60) = 5.7$, $p \leq .01$). The results of the paired t-tests showed that patients

reported on average more distress than their partners (t (60) = 2.1, p = .02) (Table I). The partners, however, reported receiving more negative transactions from the patient (t (60) = 2.6, p = .01) and partners also reported lower marital quality than the patients (t (60) = 2.3, p = .02). Female *patients* reported more distress than male *patients* (t (59) = 1.9, p = .03) and female *patients* also reported more disability (t (59) = 2.0, p = .03). Female *partners* reported receiving more negative transactions from the male patients than male *partners* from the female patients (t (59) = 2.7, p = .01).

Bland-Altman method. Following the Bland-Altman method we plotted the difference between patients' and partners' distress scores against the average of the patient and partner distress scores (see Figure 1).

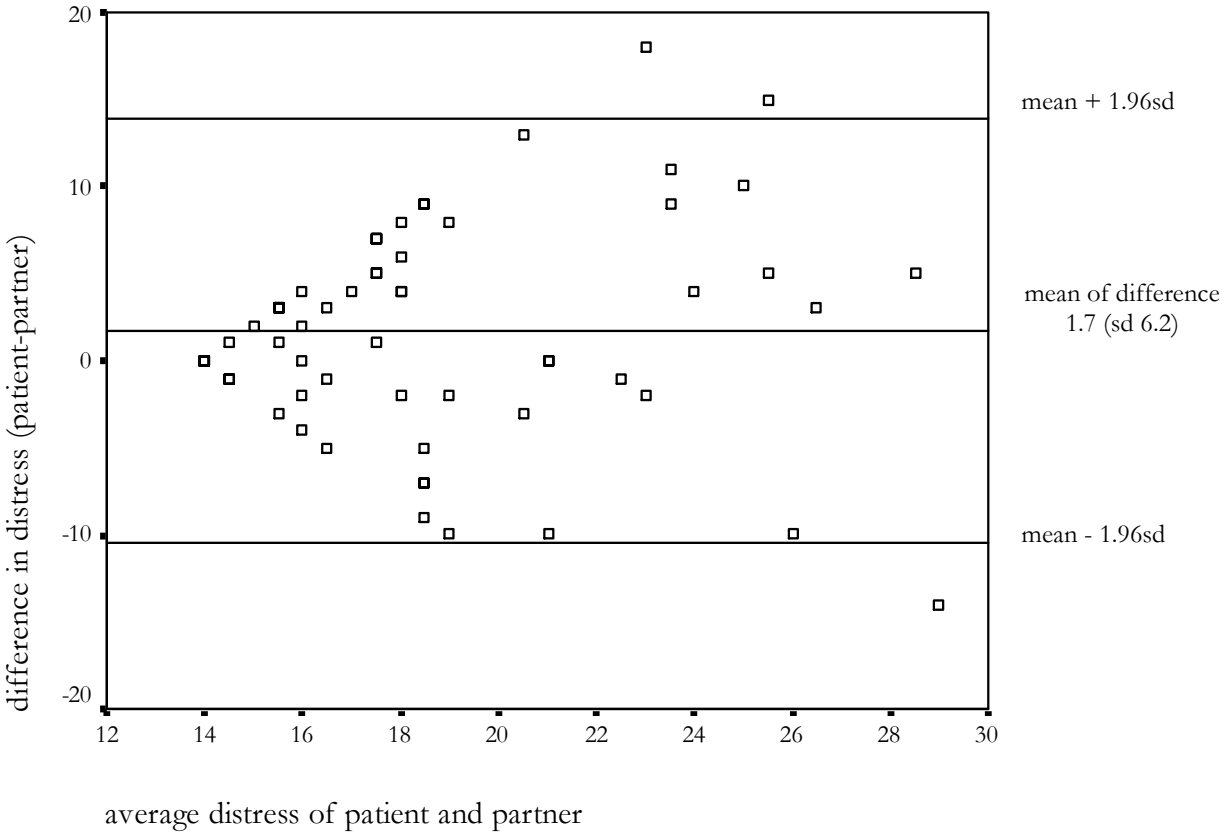

Figure 1. Distress patient and partner: differences (patient-partner) versus average of patient and partner score.

The mean difference in distress was 2.0 with a standard deviation of 6.4. In Figure 1 the horizontal lines through the graph show the 95% limits of agreement. The mean and standard deviation of the differences are not the same throughout the range of measurement: the higher the average distress level of the couple, the more the distress scores of patients and partners will differ in either direction.

The number of couples in which the patient experienced more distress than the partner (points above the mean of the difference scores) is more or less equal to the number of couples in which the partner experienced more distress than the patient (points below the mean of the difference scores). Furthermore, several couples in which both patient and partner experienced high levels of distress can be identified that may be at risk for chronic distress; these are the points to the right, near to the mean of difference line. Three possible outliers can be observed, almost exactly 5% of the observations. Therefore, none of these couples are left out from the analysis. A weak rank correlation of .19 (p = .05) was found, confirming that the absolute difference between patient and partner increases with the magnitude of the average distress level of the couple. This indication of heterogeneity is at least partly taken care of by the different patient and partner variances in the multilevel analysis.

Correlations. The correlations, reported in (see Table 2), were all in the expected direction. First we will report some important correlations between *patient* variables. *Patient*'s distress was significantly related to disability of the *patient* (r = .43). Furthermore, *patients* who reported more negative transactions from their partner reported poorer marital quality (r = -.33). With regard to the most important correlations between *partner* variables, *partner's* distress, perceived burden by the *partner*, perceived negative transactions and marital quality had correlations ranging from .38 to .63. As to the correlations between *patient* and *partner* variables, *patient's* distress and disability were positively related to *partner's* perceived burden (r = .31 and r = .45, respectively). The negative transactions perceived by the *patient* and *partner* were positively correlated, as well as the marital quality perceived by both partners (r = .41 and r = .45, respectively). Marital quality perceived by the *partner* was negatively related to *patient's* disability (r = -.23) and to negative transactions perceived by the *patients* (r = -.22).

Table 2. Correlations between study measures (N = 61 couples).

	1	2	3	4	5	6	7	8	9	10	11	12	13
Patient													
1. age													
2. education	-.19												
3. disease duration	.-.08	-.09											
4. disability	.14	-.37**	.32*										
5. distress	-.07	-.16	.00	.43**									
6. negative transactions	-.04	.24*	.13	.16	.06								
7. marital quality	.23*	-.28*	-.20	-.04	-.10	-.33*							
Partner													
8. age	.83**	-.30**	-.09	.18	-.05	-.12	.22*	.04					
9. education	-.22*	.33**	.14	-.05	.13	.13	-.22*	-.17	-.26*				
11. burden	-.03	-.18	.11	.45**	.31*	.04	-.03	-.04	-.12	-.08			
12. distress	.12	.08	-.01	.18	.20	.14	-.20	.18	-.06	-.15	.55**		
13. negative transactions	-.10	.28*	-.03	-.12	-.16	.41**	-.23*	.33**	-.23*	-.11	.22*	.38**	
14. marital quality	.07	-.13	-.20	-.23*	-.14	-.22*	.45**	-.03	.12	.08	-.54**	-.63**	-.47**

Note. * p < .05: **p < .01 (1-tailed). A higher score on a certain measure refers to more of the characteristic considered.

Multilevel analyses. The first model, the so-called empty model, served as a baseline model with just intercepts for patient and partner (see Table 3 and 4). The partners had a slightly lower mean and variance in distress. Because of the two variance components at the lower level (patient and partner variance), the intraclass correlation can be calculated by dividing the couple variance by the root of the product of the two separate total variances, i.e. 4.79 / √ (4.79 + 21.41)(4.79 + 17.00), which equals .20. This intraclass correlation coefficient can be seen as the 'general' correlation coefficient between distress of the patient and distress of the partner, representing the degree of reciprocity (or interdependence) in the reported distress.

In model 2 sociodemographics and disease duration were included as control variables and primary stressors for both patient and partner were included as explanatory variables. The model showed that part of the variance in distress of patients and partners and the variance in distress at the couple level could be explained by primary stressors of patients and partners controlling for sociodemographic characteristics and disease duration. Moreover, partner's burden was added to patient's side of the model to test whether partner's burden should be viewed as a primary stressor for patients as well. Likewise, patient's disability was included in the partner's model part. The results revealed that, controlling for gender, age, and education of patient and partner and patient's disease duration, patient's disability was a significant predictor of patient's distress ($\beta = 2.12$; $t = 2.9$), while partner's burden was not. Partner's burden was a significant predictor of the partner's distress ($\beta = 2.61$; $t = 4.7$), which was not significantly affected by patient's disability. The improvement in the model compared to the empty model was 43.3 ($df = 12$, $p = .000$). The percentage explained patient variance was 25%; the percentage explained partner variance was 38%.

Because of the dependence between patient's disability and partner's burden, interaction terms for patient and partner between disability and burden were included in the third model. By testing these interactions we investigated whether the primary stressor of patients had an indirect effect on their partner's distress, and vice versa, that is, whether the effect of patient's primary stressor was influenced by the level of their partner's primary stressor. For the partner, the interaction term was an important predictor ($\beta = 2.46$; $t = 5.0$). The effect of partner's burden on his/her distress was higher for couples in which the patient's disability was high compared to couples in which the patient's disability was low. For instance, if the patient had a disability one standard deviation higher than average, the effect of partner's burden on partner's distress was $3.17 + 1 * 2.46 = 5.63$.

Table 3: Multilevel analyses: coefficients of the predictors

Model	1		2		3		4		5	
	B	se	B	se	B	se	B	se	B	se
Patient										
Constant	19.64*	.66	18.92*	1.06	18.28*	1.11	18.39*	1.16	18.09*	1.10
Gender[1]			1.10	1.32	1.36	.130	1.28	1.33	1.48	1.26
Age			-.79	.68	-.75	.67	-.74	.68	-.44	.65
Education			-.16	.62	-.11	.61	-.16	.65	.38	.65
Disease duration			-.83	.61	-.74	.60	-.79	.61	-.62	.58
Disability			2.12*	.74	1.94*	.74	1.96*	.76	2.03*	.72
Burden			.64	.65	.89	.65	.87	.66	1.20#	.63
Disability x burden					1.03	.67	.97	.70	1.28#	.67
Negative transactions							-.04	.67	-.27	.65
Marital quality							-.25	.76	-.30	.72
Marital quality x burden									1.32*	.51
Partner										
Constant	17.95*	.60	17.34*	.60	16.42*	.53	16.46*	.50	16.07*	.49
Gender[1]			1.80#	1.09	1.22	.92	1.18	.90	1.86*	.85
Age			-.11	.49	-.12	.41	.03	.39	-.25	.37
Education			-.46	.52	-.51	.44	-.39	.41	-.07	.39
Disease duration			-.28	.52	-.05	.44	-.34	.42	-.31	.40
Disability			-.03	.62	-.48	.53	-.30	.50	-.12	.46
Burden			2.61*	.56	3.17*	.49	2.19*	.54	2.83*	.54
Disability x burden					2.46*	.49	1.90*	.49	2.16*	.46
Negative transactions							.05	.46	-.11	.43
Marital quality							-1.43*	.48	-.88	.55
Negative transactions x marital quality									-.79*	.39
Negative transactions x burden									-1.18*	.38

Note. * $p < .05$ and # $.10 > p > .05$. A higher score on a certain measure refers to more of the characteristic considered.

[1]0 = male, 1 = female

Table 4. Multilevel analyses: model properties

Model	1		2		3		4		5	
Couple variance	4.79	3.12	2.49	2.15	.75	1.76	1.10	1.63	.33	1.41
Patient variance	21.41	4.90	17.04	3.73	18.04	3.70	17.66	3.58	16.52	3.31
Partner variance	18.00	4.30	11.61	2.97	9.23	2.42	7.44	2.10	6.89	1.88
Deviance	730.9		687.6		665.4		655.5		639.1	
Explained patient variance (%)			25		26		28		36	
Explained partner variance (%)			38		56		61		68	
Intraclass correlation	.20		.15		.05		.09		.03	

For the patient a similar, though not significant effect was found: a higher partner burden increased the effect of disability on patient's distress. This model was an improvement compared to the second model, with a difference in deviance of 22.2 ($df = 2$, $p \leq .001$). The percentage explained patient variance compared to the empty model was 26%; the percentage explained partner variance compared to the empty model was 56%. Moreover, the estimated intraclass correlation was greatly reduced, to .05, indicating that the interaction terms captured a large part of the correlation between patient's and partner's distress.

Next, the secondary stressors – negative transactions and marital quality – were entered in the model. Negative transactions perceived by patient or partner did not have a direct effect on patient's or partner's distress. Marital quality perceived by the patient did not seem to be indicative of patient's distress, but marital quality perceived by the partner was a significant predictor of partner's distress ($\beta = -1.43$ and $t = 3.0$). The difference in deviance of model 4 with model 3 was 9.9 ($df = 4$, $p = .04$), which showed the model was an improvement. The percentages explained patient and partner variance both increased as well, to 28% and 61%; the intraclass correlation coefficient was now .09.

To explore whether the secondary stressors (negative transactions and marital quality) had indirect effects or influenced the effects of the primary stressors (disability and burden), we extended the model with two-way and three-way interactions between disability, negative transactions and marital quality and between burden, negative transactions and marital quality. In a backward selection procedure, we kept only the significant interaction effects. The resulting model (presented as model 5 in Table 3) had three two-way interactions: one for patients,

partner's burden x marital quality perceived by the patient (β = 1.32 and t = 2.6) and two for partners, perceived negative transactions x marital quality (β = -.79 and t = 2.1) and perceived negative transactions x partner's burden (β = -1.18 and t = 3.1).

The first effect indicated that for a low value of partner's burden, the negative (thus favorable) effect of marital quality as perceived by patient on his/her distress was stronger. For patients with a highly burdened partner, marital quality had a positive (detrimental) effect. In the patient part of model 5, partner's burden and the interaction between disability and burden was now much more pronounced as well, on the border of significance (respectively β = 1.20 and t = 1.9; β = 1.28 and t = 1.9).

The interaction effect between negative transactions and partner's burden on partner's distress indicated that for a higher value of negative transactions the distress-reducing effect of marital quality was stronger. The interaction of negative transactions with burden can be interpreted similarly: when partners perceived more negative transactions the effect of burden on the partner's distress was reduced. In the partner part of model 5, the effect of gender had become larger and significant (β = 1.86 and t = 2.2), indicating that women experienced more distress than men, all other circumstances being equal.

The final model was an improvement over the previous model with a difference in deviance of 13.8 (df = 3, p = .003). The percentage explained patient variance compared to the empty model was 36%; the percentage explained partner variance compared to the empty model was 68%. The intraclass correlation was reduced to .03.

In summary, our hypothesis that patient's disability was a primary stressor for patients, and that partner's burden was a primary stressor for partners was confirmed. The hypothesis that patient's disability was not a primary stressor for partners, and that partner's burden was not a primary stressor for patients was confirmed as well, in the sense that no direct effect was found, except for a borderline significant effect of burden on patient's distress in the final exploratory model. An indirect effect for partners was found however, and to a lesser extent for patients as well, in the form of interaction effects between patient's disability and partner's burden. The hypothesis that negative transactions and marital quality were secondary stressors was only confirmed for partners. The analysis showed a weak direct effect of marital quality on partner's distress where its strength was influenced by negative transactions between patients and partners through an interaction effect. The effect of marital quality on patient's distress depended on partner's burden. The second interaction effect of a primary and secondary

stressor found in the exploratory analysis indicated that negative transactions perceived by the partner influenced the effect of burden on his/her distress.

Discussion

In this study we investigated simultaneously which primary and secondary stressors determine distress in rheumatoid arthritis patients and their partners. Our study is one of the few studies (10;11;20) that not only investigated the effects of RA on patients, but also on their partners. By using a multilevel approach in our analysis, our study distinguishes itself from these previous studies. The Actor-Partner-Interdependence Model, distinguishing the different roles of patient and partner while acknowledging the interdependence in their distress scores, was found to be quite useful for the analysis. Guided by Pearlin et al.'s (17) construct of stress proliferation, we were able to distinguish some mechanisms through which RA affects patients and their partners. In line with previous findings, we found that for RA patients the primary stressor was indeed embedded in their disease, through the degree of disability experienced. For the partners, in line with previous studies (11;48), the primary stressor was the burden experienced. Both effects seem to be of similar strength. In accordance with the study of Manne and Zautra (20), patient's disability was found not to be a primary stressor for the partner. However, disability was found to have an indirect effect on partner's distress, through the interaction with partner's burden. A higher disability increased the effect burden had on partner's distress. A similar, although much weaker, interaction effect of partner's burden on the effect of disability on patient's distress was found in addition to a possible direct effect of partner's burden. The interaction effect may indicate that, possible as a result of the intimacy in the relationship, the patient is not only preoccupied with her or his own physical condition, and the partner not only with his or her own burden, but both are aware of their partner's circumstances. A further indication that this mechanism might explain the interdependence between patient and partner's distress was found in the decrease of the intraclass correlation from .20 in the first model to .03 in the final exploratory model.

Interestingly, partners reported receiving more negative transactions from the patients than vice versa, which may indicate that patients handle their pain and frustration more openly and visibly than the partner by reacting in a negative and sometimes even hostile way to their partners. Partners also reported worse marital quality than the patients, which could be indicative of an imbalance of give-and-take between patient and partner caused by the presence of a

chronic disease. In later stages of RA, such as in our sample, partners may have given more support than they received from their partner and may have received more negative transactions from their partners than their partner received from them, which in turn may affect perceived marital quality (49).

We expected that negative transactions between patient and partner and poor marital quality were secondary stressors for patients, but the results only partly support this. In line with our expectations, for the partners, negative transactions and marital quality were shown to be secondary stressors for the partners. In contrast with our expectations, patients' distress was not determined or influenced directly by the negative transactions with their partner or by the quality of their marriage. Through an interaction effect with partner's burden, however, an indication of a weak effect of marital quality on patient's distress was obtained. This could again be interpreted as a sign of the interdependence between patient's and partner's distress. In high quality relations with relatively low burden for the partner, patient's distress is lower than in high quality relations where the partner experiences high burden.

RA affects partners through patients' behavior which may affect the perceived quality of the marriage. Distressed patients may show more negative behavior which could trigger conflicts with their partners, who in turn may perceive poorer marital quality and become more distressed for that reason. Exploratory analyses showed an even more complex mechanism through which these secondary stressors possibly influence partners' distress. Marital satisfaction seemed to buffer the effect of negative transactions on distress of the partner. If the partner perceived the marital quality as good, the negative effect of negative transactions on the partner's distress was less than if the partner perceived the marital quality as bad. Furthermore, negative transactions also influenced the effect of burden on distress of the partner. In contrast with what might be expected, for a high degree of negative transactions perceived by the partner, the effect of partner's burden on his or her distress was reduced. This would point to a mechanism where a higher degree of negative transactions lowers the emotional impact of perceived burden.

Although prior findings (10;11) showed that partners had elevated levels of distress compared to the general population, patients and partners in our study were, on average, less distressed than the general Dutch population. There are several explanations for this. Firstly, our couples may not be representative of all RA couples. Analysis of the non-response of the partners revealed that those patients whose partners participated reported better marital quality than patients whose partners did not participate. As a result our sample may have been

overrepresented by couples with successful marriages and consequently with low levels of distress. Secondly, our sample consisted of older RA couples. Older RA patients may experience less distress (50;51). Distress may be intensified in younger couples compared to older couples, since the intrusiveness of RA on younger lives is higher (52). A third explanation concerns the assessment of psychological distress. The nature of the items and answer categories of the General Health Questionnaire, may have contributed to the low values of distress. Patients were asked to compare their current status with their usual state of mind. This may be colored, however, by other psychological processes taking place. Patients may, for example, change their internal standards and the values and life goals they find important. After having had RA for a long time, patients may not compare themselves with their psychological well-being before the diagnosis of RA, but with their 'new' — usually higher — distress level.

Due to the relative small sample size and the rather elaborated models, we did not investigate gender differences beyond the main effect of RA on patients and partners. For patients no significant differences between men and women were found in the models; their higher disability seems to explain the higher distress experienced by female patients. The model does not offer an explanation yet why female partners experienced more distress. It may be necessary to pay more attention to the influence of gender on the patient and partner roles in future research.

For future research it is also important to focus more on the interaction between patient and partner in early stages of RA, to investigate changes over time and to take secondary stressors into consideration. The constructs of primary and secondary stressors may help to understand the variability in outcomes. Moderating resources such as coping and social support are not the only factors that explain individual variation in outcomes. Patients with RA and their partners may be differently distressed due to a different exposure to secondary stressors.

A better understanding of the mechanisms through which RA affects patients and partners could help professionals in rehabilitation to aim intervention not only at ameliorating the primary condition of the patient, but also at minimizing expansion of primary stressors and the generation of secondary stressors. Participation of partners in intervention programs may be more effective if more emphasis is given to the interaction between patient and partner and how they can help each other in counteracting the proliferation of stressors.

References

(1) Gordon DA, Hastings DE. Rheumatoid arthritis. Clinical features of rheumatoid arthritis: early progressive and late disease. In: Klippel JH, Dieppe PA, editors. Practical rheumatology. London: Mosby, 1997: 169-182.

(2) Hannan MT. Epidemiologic perspectives on women with arthritis: an overview. Arthritis Care and Research 1996; 9:424-434.

(3) Evers AW, Kraaimaat FW, Geenen R, Bijlsma JW. Psychosocial predictors of functional change in recently diagnosed rheumatoid arthritis patients. Behaviour Research and Therapy 1998; 36(2):179-193.

(4) Doeglas DM, Suurmeijer Th, Krol B, Sanderman R, Van Leeuwen M, Van Rijswijk M. Work disability in early rheumatoid arthritis. Annals of the Rheumatic Diseases 1995; 54:455-460.

(5) Fex E, Larsson BM, Nived K, Eberhardt K. Effect of rheumatoid arthritis on work status and social and leisure time activities in patients followed 8 years from onset. Journal of Rheumatology 1998; 25(1):44-50.

(6) Van Jaarsveld CH, Jacobs JW, Schrijvers AJ, Albada-Kuipers GA, Hofman DM, Bijlsma JW. Effects of rheumatoid arthritis on employment and social participation during the first years of disease in The Netherlands. British Journal of Rheumatology 1998; 37(8):848-853.

(7) Wiener CL. The burden of rheumatoid arthritis. In: Strauss AL, editor. Chronic illness and the quality of life (2nd ed.). 1984: 88-98.

(8) Evers AW, Kraaimaat FW, Geenen R, Jacobs JW, Bijlsma JW. Longterm predictors of anxiety and depressed mood in early rheumatoid arthritis: a 3 and 5 year followup. Journal of Rheumatology 2002; 29(11):2327-2336.

(9) Katz PP, Yelin EH. The development of depressive symptoms among women with rheumatoid arthritis. The role of function. Arthritis and Rheumatism 1995; 38(1):49-56.

(10) Revenson TA, Majerovitz SD. The effects of chronic illness on the spouse. Social resources as stress buffers. Arthritis Care and Research 1991; 4(2):63-72.

(11) Walsh JD, Blanchard EB, Kremer JM, Blanchard CG. The psychosocial effects of rheumatoid arthritis on the patient and the well partner. Behaviour Research and Therapy 1999; 37(3):259-271.

(12) Jacobi CE, Van den Berg B, Boshuizen HC, Rupp I, Dinant HJ, Van den Bos GA. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. Rheumatology (Oxford) 2003; 42(10):1226-1233.

(13) Riemsma RP, Taal E, Rasker JJ. The burden of care for informal caregivers of patients with rheumatoid arthritis. Psychology and Health 1999; 14:773-794.

(14) Revenson TA, Majerovitz SD. Spouses support provision to chronically ill patients. Journal of Social and Personal relationships 1990; 7:575-586.

(15) Suurmeijer ThPBM, Van Sonderen FLP, Krol B, Doeglas DM, Van den Heuvel WJA, Sanderman R. The relationship between personality, supportive transactions and support satisfaction, and mental health of patients with early rheumatoid arthritis. Results from the Dutch part of the EURIDISS study. Social Indicators Research 2005; 73(2):179-188.

(16) Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. Gerontologist 1990; 30(5):583-594.

(17) Pearlin LI, Aneshensel CS, Leblanc AJ. The forms and mechanisms of stress proliferation: the case of AIDS caregivers. Journal of Health and Social Behavior 1997; 38:223-236.

(18) Coyne JC, Kessler RC, Tal M, Turnbull J, Wortman CB, Greden JF. Living with a depressed person. Journal of Consulting and Clinical Psychology 1987; 55:347-352.

(19) Krantz SE, Moos RH. Functional and life context among spouses of remitted and non-remitted depressed patients. Journal of Consulting and Clinical Psychology 1987; 55:353-360.

(20) Manne SL, Zautra AJ. Couples coping with chronic illness: women with rheumatoid arthritis and their healthy husbands. Journal of Behavioral Medicine 1990; 13(4):327-342.

(21) Covic T, Adamson B, Spencer D, Howe G. A biopsychosocial model of pain and depression in rheumatoid arthritis: a 12-month longitudinal study. Rheumatology (Oxford) 2003; 42(11):1287-1294.

(22) Fitzpatrick R, Newman S, Archer R, Shipley M. Social support, disability and depression: a longitudinal study of rheumatoid arthritis. Social Science and Medicine 1991; 33(5):605-611.

(23) Hyman MD. Disability and patients' perceptions of preferential treatment: some preliminary findings. Journal of Chronic Diseases 1971; 24(5):329-342.

(24) Martire LM, Stephens MAP, Druley JA, Wojno WC. Negative reactions to received spousal care: predictors and consequences of miscarried support. Health Psychology 2002; 21(2):167-176.

(25) Revenson TA, Schiaffino KM, Majerovitz SD, Gibofsky A. Social support as a double-edged sword: the relation of positive and problematic support to depression among rheumatoid arthritis patients. Social Science and Medicine 1991; 33(7):807-813.

(26) Danoff-Burg S, Revenson TA, Trudeau KJ, Paget SA. Unmitigated communion, social constraints, and psychological distress among women with rheumatoid arthritis. Journal of Personality 2004; 72(1):29-46.

(27) Lanza AF, Cameron AE, Revenson TA. Perceptions of helpful and unhelpful support among married individuals with rheumatic diseases. Psychology and Health 1995; 10(6):449-462.

(28) Manne SL, Zautra AJ. Spouse criticism and support: their association with coping and psychological adjustment among women with rheumatoid arthritis. Journal of Personality and Social Psychology 1989; 56:608-617.

(29) Roth-Roemer SL, Robinson SE. The influence of marital quality and social support on the health of women with rheumatoid arthritis. Women's Health: Research on Gender, Behavior, and Policy 1996; 3:195-205.

(30) Euridiss. European research on incapacitating diseases and social support. International Journal of Health Sciences 1990; 1(3):217-228.

(31) Suurmeijer TP, Waltz M, Moum T, Guillemin F, Van Sonderen FL, Briancon S et al. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis and Rheumatism 2001; 45(2):111-121.

(32) Goldberg D, Williams P. A user's guide to the General health questionnaire. London: The NFER-Nelson publishing Company ltd., 1988.

(33) Sanderman R, Stewart R. The assessment of psychological distress: psychometric properties of the General Health Questionnaire (GHQ). International Journal of Health Sciences 1990; 3(1):195-202.

(34) Krol B, Sanderman R, Moum T, Suurmeijer Th, Doeglas D, Robinson I et al. A comparison of the General health questionnaire 28 between patients with rheumatoid arthritis from the Netherlands, France, Sweden and Norway. European Journal of Psychological Assessment 1994; 10(2):93-101.

(35) Wolfe F, Skevington SM. Measuring the epidemiology of distress: the rheumatology distress index. Journal of Rheumatology 2000; 27(8):2000-2009.

(36) Suurmeijer Th, Doeglas D, Moum T, Briancon S, Krol B, Sanderman R et al. Disability as measured by the groningen activity restriction scale (GARS): a cross-national reliability and validity study. Scandinavian Journal of Rheumatology 1994; 23(97 (suppl)):16.

(37) Doeglas D, Krol B, Guillemin F, Suurmeijer Th, Sanderman R, Smedstad L et al. The assessment of functional status in rheumatoid arthritis: a cross cultural, longitudinal comparison of the Health Assessment Questionnaire and the Groningen Activity Restriction Scale. Journal of Rheumatology 1995; 22(10):1834-1843.

(38) Robinson BC. Validation of a Caregiver Strain Index. Journal of Gerontology 1983; 38(3):344-348.

(39) Van Sonderen E. Het meten van sociale steun [Measuring social support]. Groningen: University of Groningen, 1991.

(40) Arrindell WA, Boelens W, Lambert H. On the psychometric properties of the Maudsley Marital Questionnaire (MMQ): evaluation of self-ratings in distressed and "normal" volunteer couples based on the Dutch version. Personality and Individual Differences 1983; 4(3):293-306.

(41) United Nations Educational Scientific and Cultural Organization. International Standard Classification of Education. Paris: 1976.

(42) Arnett FC, Edworthy SM, Bloch DA, McShane DJ, Fries JF, Cooper NS et al. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis and Rheumatism 1988; 31(3):315-324.

(43) Koeter MWJ, Ormel J. General Health Questionnaire: Nederlandse bewerking. Handleiding. Lisse: Swets Zeitlinger, 1991.

(44) Bland J, Altman D. Measuring agreement in method comparison studies. Statistical Methods in Medical Research 1999; 8:135-160.

(45) Kenny DA', Cook W. Partner effects in relationship research: Conceptual issues, analytic difficulties, and illustrations. Personal Relationships 1999; 6:433-448.

(46) Campbell L, Kashy DA. Estimating actor, partner, and interaction effects for dyadic data using PROC MIXED and HLM: A user-friendly guide. Personal Relationships 2002; 9:327-342.

(47) Snijders TAB, Kenny DA. The social relations model for family data: a multilevel approach. Personal Relationships 1999; 6:471-486.

(48) DasChagas Medeiros MM, Ferraz MB, Quaresma MR. The effect of rheumatoid arthritis on the quality of life of primary caregivers. Journal of Rheumatology 2000; 27(1):76-83.

(49) Kuijer RG, Buunk BP, Ybema JF, Wobbes T. The relation between perceived inequity, marital satisfaction and emotions among couples facing cancer. British Journal of Social Psychology 2002; 41(Pt 1):39-56.

(50) Cassileth BR, Lusk EJ, Strouse TB, Miller DS, Brown LL, Cross PA et al. Psychosocial status in chronic illness A comparative analysis of six diagnostic groups. New England Journal of Medicine 1984; 311(8):506-511.

(51) Wright GE, Parker JC, Smarr KL, Johnson JC, Hewett JE, Walker SE. Age, depressive symptoms, and rheumatoid arthritis. Arthritis and Rheumatism 1998; 41(2):298-305.

(52) Devins GM, Edworthy SM, Guthrie NG, Martin L. Illness intrusiveness in rheumatoid arthritis: differential impact on depressive symptoms over the adult lifespan. Journal of Rheumatology 1992; 19(5):709-715.